



OWEN
multiple defects
and surgeries

Small Hearts – Big Challenges

Congenital heart defects in children and youth: 2011

Often viewed as a problem of adults, cardiovascular disease also exacts a terrible toll on the young and their families.

Congenital heart defects are problems with the heart's structure that are present at birth, such as holes in the heart, narrowed or leaky valves and malformed or missing vessels/heart chambers.

At least 35 types of defects are recognized. They strike without regard to socio-economic, racial or cultural background. In most cases we don't know why defects occur, but some causes have been identified.

Several genetic syndromes (such as Down, DiGeorge, Williams, Alagille, and Noonan syndromes) have cardiac malformations as well as defects in other organ systems.

Many maternal exposures early in pregnancy are associated with congenital heart defects. These include:

- some medications for seizures, acne or bipolar disorder
- rubella (German measles), other viral diseases, diabetes
- alcohol abuse, street drugs, certain chemicals.

Eight of every 1,000 babies born each year have a heart defect. That's almost 1% of live-born infants.

The chances of a sibling also being born with a heart defect are about 2-3%. While this is higher than the general 1% rate, it's still a relatively small chance.

Although exact causes for most congenital defects aren't known, remaining healthy and avoiding certain exposures may be helpful. Fetal echocardiograms (ultrasounds) may help detect problems as early as mid-pregnancy.

Impact on families and on our society

Sometimes the heart defect is so mild there are no outward symptoms. Sometimes it's so severe that the newborn becomes

ill soon after birth. In still other cases, signs and symptoms occur only in later childhood.

Most of these children can be helped by surgery even if the defect is severe. About 9,200 of these newborns require invasive treatment or die before age 1.

Congenital cardiovascular defects are the most common cause of infant death resulting from birth defects: 24% of infants who die of a birth defect have a heart defect.

Congenital heart defects directly caused or contributed to 5,643 deaths in 2007.

Beyond the death toll and physical and mental suffering, congenital heart defects also have a steep economic price tag. In 2004, hospital costs for congenital heart defect conditions totaled \$2.6 billion.

The death rate for congenital heart defects has been declining. From 1979 to 1997, death rates declined 39%, and deaths tended to occur at progressively older ages.

Nevertheless, 45% of deaths still occurred in infants under 1 year of age. The mortality rate varies considerably according to type of defect. From 1997 to 2007, death rates for these defects declined 33.3% and the actual number of deaths declined 23.8%.

But there is reason for hope. Thanks to medical research, most babies with congenital heart defects now survive to adulthood. Up to 1.3 million people in the U.S. are living with a heart defect they've had since birth. About half of them are under age 25.

However, survivors – particularly those with more complex defects – are more likely to develop additional heart problems later in life.



NICHOLAS
heart surgery at two days old



COOPER
surgery to correct
narrowed aorta



JOESHUA
rare rewiring
of arteries and vessels



How we help families and healthcare providers cope with **Congenital Heart Defects**

Each year, about 36,000 U.S. babies are born with a heart defect. We're working to reduce this number by helping more babies be healthy. Since 2005, we've committed \$61.4 million to research relating to children's health and we're working on several other fronts to prevent and treat these devastating events.

Funding pediatric heart research

We fund research on the causes and possible cures for congenital heart defects and other pediatric heart disease.

Last year (fiscal year 2009-10), we spent more than \$106 million on heart and stroke research nationwide. Of that amount, approximately \$9.4 million was spent on pediatric research. We funded 422 pediatric research studies from 2005 through 2010 at a cost of \$61.4 million.

Our grants focus on basic and clinical research studies and investigators who are starting their research training. Larger, federally funded clinical studies often lead to breakthroughs, but researchers must have considerable experience to obtain them. We make a huge contribution by providing funding for early training. Our research funds are distributed in proportion to the number of applications received for each topic.

Our funding for pediatric cardiovascular research is second only to the federal government. Research topics we fund include: heart development before birth, congenital heart defects, Kawasaki disease, acute rheumatic fever, stroke and sickle cell anemia in children, and maintaining heart-health in children.

Advocating for lifesaving public policies

We also fight congenital heart disease through advocacy efforts in Washington, DC. On our federal Lobby Day, children and adults with congenital heart defects and hundreds of other volunteer advocates urge their lawmakers to:

- increase federal funding for pediatric research and educational programs
- improve access to specialized programs of care for survivors and programs to help women reduce risk factors
- eliminate health insurance penalties for pre-existing conditions in children and adults.

Communicating research results

In recent years, there's been a revolution in caring for children with congenital heart defects. Advances in diagnosis and surgery have made it possible to repair most defects, even those

once considered hopeless. Many people with these defects now reach adulthood and live full, active lives.

Our *Council on Cardiovascular Disease in the Young* helps develop scientific statements/guidelines and organize scientific conferences to update health professionals' understanding of the anatomy, diagnosis and medical/surgical management of congenital heart disease.

We've also issued guidelines to help prospective mothers lower the risk of congenital heart defects in their babies:

- Take a multivitamin with folic acid daily.
- Get rubella and flu shots; avoid people with fever-related illness.
- Get preconception and prenatal care, with specific attention to detecting and managing diabetes.
- Discuss prescription and other medication use with a doctor.
- Avoid exposure to organic solvents.

Mended Little Hearts

Mended Little Hearts, a support program for parents of children with congenital heart defects and heart disease, offers resources

and a caring support network as families find answers and move forward to find healing and hope. To learn if there is a group in your area, to request information on forming a group, or to

discover other ways you can help, call 1-888-HEART99.

Online education

Our association's Web site (heart.org/congenital) has information on conditions, diagnostic tests, treatments and ongoing care needs for children and adults with congenital heart disease.

Congenital Heart Defect Awareness Week (the second week in February) is sponsored by the Congenital Heart Information Network. Visit <http://tchin.org> to learn more.



How You Can Help

Your donation will help fund research, education and public advocacy to help families and healthcare professionals detect, treat and even prevent the congenital heart defects that affect so many precious little lives every year.